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ABSTRACT

British parents of children with severe/multiple learning disabilities were surveyed to determine the parents' wishes, needs, and satisfaction with the child's school placement. Eighty parents responded (a 53 percent response rate) to a mailed questionnaire. At present, the majority of children described as having severe learning difficulties are educated in special schools where they are increasingly integrated with less severely disabled children. Responses to questions concerning what parents want the child to learn, level of satisfaction with what is being taught by subject area, actual and desired participation of parents in the child's education, and types of support services received are rank ordered. The parents' information needs, present and future concerns for their child, preferred future housing options for the child, and preferred future work for the child are detailed. Findings indicate that the majority of parents are generally satisfied with their child's special school placement. A priority for their child's learning is the acquisition of communication skills, with social, motor, and leisure skills also being important. The achievement of academic skills ranks less highly, and there was less satisfaction with the teaching of academic skills than with other skills. The paper concludes that some parents appear to prefer special schooling for their children, from a perceived lack of resources or expertise to be found in regular schools. (DB)

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ED 403 722

Views of British Parents about Special Education Services for their Child with Mental Disabilities

by

Dawn B. Male

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Paper presented at the 10th World Congress of the International Association for the Scientific Study of Intellectual Disabilities (IASSID)

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Introduction

The last twenty years or so have witnessed enormous changes in the field of special education in Britain. At the centre of these changes has been the increased inclusion in 'ordinary' schools of children with learning difficulties and disabilities. Alongside this, such arrangements as open enrolment in schools (under the terms of the 1988 Education Reform Act) suggest a philosophy of parents as 'purchasers' of education services. More recently, the 1993 Education Act has given parents of children with special educational needs (SENs) the right to express a preference for a particular maintained school.

Whilst this desire to include parents of children with SENs in the decision-making process has been strongly stated through the legislation, relatively little is known in the research literature about their actual wishes, needs and preferences. This is particularly the case for certain groups of parents, including parents of children with severe/profound and multiple learning difficulties (mental disabilities).

This paper reports on the findings of a research study, conducted via a postal questionnaire, which aimed to elicit the wishes, needs and satisfaction with various services of parents of children with severe/profound and multiple learning difficulties in Britain. The particular areas reported here concern parents' views regarding their child's education, services received, type of housing and employment preferred and present and future concerns.

Prior to this, a brief overview of the organisation of special education in Britain.

The organisation of special education in Britain

Special education in Britain is 'educational provision which is additional to, or otherwise different from, the educational provision made generally for children in schools maintained by the local authority'. Planning for special education is based on the assumption that about 20% of children will need special educational provision and that about 2% of these will need provision which is determined by the local education authority (LEA) and formalised within a Statement of Special Educational Need. Many of the children within the 2% band will attend special schools, most usually grouped according to nature of difficulty - even though, since the passing of the 1981 Education Act, categories of disability have been replaced with a needs-led view of provision.

Prior to 1970 the children with whom this paper is concerned were described as 'ineducable' and were the responsibility of District Health Authorities (DHAs). With the passing of the 1970 Education (Handicapped Children) Act the legal division between children who were educable and those who were not was removed. The Act thus brought 'ineducable' children under the responsibility of LEAs.

At the present time in Britain the majority of children now described as having severe learning difficulties (SLD) are educated within special schools. Children described as having profound and multiple learning difficulties i.e those with profound mental retardation and at least one additional impairment to vision, hearing or movement (Hogg *et al.*, 1987) are considered a 'subset' of the SLD population and, until recently, have been educated mainly (but not exclusively) in so-called 'Special Care Units' (SCUs) within SLD schools: these are classes in a school for SLD children which are intended to cater *specifically* for children with profound and multiple learning difficulties (Evans and Ware, 1987).

Recent trends suggest that these SCUs are disappearing and that children with profound learning difficulties are now being educated alongside their SLD peers in the mainstream of SLD schools.

The research study

Who responded to the questionnaire?

Eighty parents responded to the questionnaire. This was a 53% response rate. A third lived in an inner city area, almost a half lived in an urban area and the remainder lived in a rural area. About half the parents completed their education at secondary school, just over a quarter had attended a college of further education or equivalent, and about the same proportion had attended a college of higher education or equivalent.

Half of the parents described themselves as white British. The remainder of the sample was divided almost equally between other British, black Caribbean, other black, Indian, Pakistani, other Asian, and other/mixed. No parent indicated that s/he was Bangladeshi.

Who were the children?

The average age of the children was 6 years 9 months. The range was 2 years to 10 years 11 months. A third of the pupils were girls and two-thirds were boys.

In addition to their severe learning difficulties 39% had physical difficulties, 13% had Down syndrome, 20% were described as autistic and 32% had challenging behaviour. A quarter of the children were partially sighted and 4% had no vision. Slightly smaller proportions had partial hearing or did not hear.

In what type of setting are the children placed?

All children attend special schools for those with severe/profound and multiple learning difficulties. Almost three-quarters are in an ordinary class in a special (SLD) school and the remainder are in a special class in a special (SLD) school.

How satisfied are the parents with their child's placement?

Table 1 shows the mean level of parental satisfaction with their child's placement.

Table 1
Level of Satisfaction with Placement

Current placement	Level of satisfaction
class in a special school	4.31 *(sd 0.85)*
special class in a special school	3.32 *(sd 1.29)*

5 = very satisfied; 4 = satisfied; 3 = somewhat satisfied; 2 = not very satisfied; 1 = not satisfied

It can be seen from the table that the mean rating in terms of satisfaction for children placed in a class in a special school is 4.31 (with a rating of 4 being equivalent to 'satisfied'). For children placed in a special class in a special school there is less satisfaction, with the mean rating being 3.32 (equivalent to 'somewhat satisfied').

In comparison to their child's current placement, would parents prefer any alternative placement?

Table 2 shows parents' preferences for other placements.

Table 2
Preference for Other Placements

Type of setting preferred	% choosing
special class/special school	1.5%
class in special school	1.5%
special class/ordinary school	20.5%
ordinary class/ordinary school	0%
different type of special school	6.5%
no change	70%

It can be seen that the majority of parents want 'no change' in terms of their child's placement. Thus, whether their child is in a class in a special school or a special class in a special school, the majority of parents prefer their child to remain there. The second preferred option for just over a fifth of parents is a special class in an ordinary school. No parent would prefer their child to be placed in an ordinary class in an ordinary school.

When parents elaborated on their reasons for preferring that their child remains in a special school they almost always referred to the perceived lack of resources and perceived lack of specialist expertise of teachers in mainstream schools. For other parents, practical considerations informed their preferences:

> *'I am happy the way things are. She goes to a special school. They take her and bring her back by bus and that's enough. I manage.'*

Of the remaining minority of parents who would prefer another type of special school for their child it was always a special school for children with autism which was mentioned.

What do parents want their children to learn and how satisfied are they with how it is being taught?

Table 3 shows the rank order of responses to the question 'What do you want your child to learn at this time?'

Table 3
What Parents Want Their Child to Learn

Area of learning	Level of importance
communication skills	4.71 *(sd 0.75)*
social skills	4.41 *(sd 1.03)*
motor skills	4.41 *(sd 1.04)*
leisure, recreational, play skills	4.19 *(sd 0.96)*
community skills	3.90 *(sd 1.46)*
academic skills	3.90 *(sd 1.36)*
skills in arts and crafts	3.76 *(sd 1.20)*
vocational skills	3.0 *(sd 1.50)*
domestic skills	2.75 *(sd 1.39)*

5 = very important; 4 = important; 3 = somewhat important; 2 = not very important; 1 = not important

According to the parents in the sample the most important area of learning for their child is communication, with this being awarded a mean rating of 4.71 (with 4 being 'important' and 5 being 'very important'). Social skills; motor skills; leisure, recreational and play skills are also all rated as being important. Academic skills - whilst still being considered important by the parents - rank only fifth and are considered to be as equally important as community skills. Domestic skills - which include 'self help' skills - are considered by the parents as only being 'somewhat important'/'not very important'.

Table 4 shows the parents' level of satisfaction with what is being taught.

Table 4
Level of Satisfaction With What is Being Taught

Area of learning	Level of satisfaction
motor skills	3.97 *(sd 0.98)*
leisure, recreational, play skills	3.63 *(sd 1.08)*
domestic skills	3.63 *(sd 1.16)*
communication skills	3.52 *(sd 1.35)*
social skills	3.49 *(sd 1.30)*
skills in arts and craft	3.49 *(sd 1.10)*
community skills	3.19 *(sd 1.38)*
academic skills	3.06 *(sd 1.32)*
vocational skills	2.94 *(sd 1.17)*

5 = very satisfied; 4 = satisfied; 3 = somewhat satisfied; 2 = not very satisfied; 1 = not satisfied

On the whole parents are satisfied or somewhat satisfied with what is being taught to their child, with the highest level of satisfaction being awarded to the teaching of motor skills. The teaching of academic skills is viewed less favourably by parents, with the mean rating being 'somewhat satisfied'/'not very satisfied'.

In what ways are parents involved in their child's education and in what ways would they like to be involved?

Table 5 shows parents' actual and desired level of participation in their child's education.

Table 5
Actual and Desired Level of Participation in Child's Education

Type of participation	Actual participation	Desired participation
talking to child's teacher	3.96 *(sd 0.90)*	4.17 *(sd 0.72)*
providing information at planning meeting	3.68 *(sd 1.18)*	3.95 *(sd 1.00)*
talking to child's headteacher	3.27 *(sd 1.10)*	3.36 *(sd 1.04)*
suggesting appropriate placement for child	3.26 *(sd 1.36)*	3.55 *(sd 1.15)*
suggesting appropriate learning goals	3.25 *(sd 1.17)*	3.75 *(sd 0.91)*
participating in school events	2.73 *(sd 1.18)*	3.17 *(sd 1.09)*
talking to child's therapist	2.64 *(sd 1.20)*	3.87 *(sd 1.04)*
participating in advocacy activities	2.06 *(sd 1.30)*	2.73 *(sd 1.40)*
participating in classroom activities	2.03 *(sd 1.04)*	3.04 *(sd 1.09)*

5 = very often; 4 = often; 3 = occasionally; 2 = not very often; 1 = never

It can be seen that the highest level of actual participation for parents is talking to their child's teacher, with this occurring - on average - often. Much less likely is participating in school or classroom events or activities, participating in advocacy activities (for example, parents' groups) or talking to their child's therapist. Overall, participation in these activities occurs occasionally or not very often.

In terms of desired participation, parents want a high level of involvement in most activities, but particularly want to be involved in talking to their child's teacher and therapist and providing information at planning meetings. Furthermore, for every activity, they want to participate more than they actually do. However, for some parents there are practical problems associated with being involved in a school which is not their child's local school:

> *'I would like to be more involved but because it's a special school it's a long way away and I don't have my own transport... it's different when the school is just around the corner.'*

What type of support services do parents receive for their child? How satisfied are they with these services? Would they like to receive these services if they do not currently do so?

Table 6 shows the percentage of parents who receive a particular service, their level of satisfaction with these services and the percentage of parents who would like to receive a service which they currently do not receive.

Table 6
Services Received and Desired; Level of Satisfaction

Service	% Receiving service	Level of satisfaction	% Wanting service
transportation assistance	73%	4.05 *(sd 1.05)*	10%
medical or related services	49%	3.82 *(sd 1.05)*	13.5%
interaction with other parents	42%	3.57 *(sd 1.14)*	20%
respite care	44%	3.51 *(sd 1.15)*	19%
special equipment/aids	31%	3.29 *(sd 1.37)*	27.5%
caseworker	15%	3.09 *(sd 1.64)*	21%
parent or family counselling	5%	2.25 *(sd 1.50)*	20%

5 = very satisfied; 4 = satisfied; 3 = somewhat satisfied; 2 = not very satisfied; 1 = not satisfied

As shown, the service received by most parents - and with which there is the highest level of satisfaction - is transportation assistance. By contrast, the service received by the smallest proportion of parents - and with which there is the least amount of satisfaction - is parent or family counselling. For the remaining services parents indicate that, in general, they are somewhat satisfied.

In terms of apparent service 'gaps' this is most marked for special equipment/aids, with over a quarter of the parents in the sample not receiving the service but expressing a desire to do so. Similarly, around a fifth of parents do not receive - but want - interaction with other parents, respite care, a caseworker and/or parent or family counselling.

How important to parents is information in the following areas? Would they like to receive more information in these areas? How would they like to receive this information?

Table 7 shows parents' views regarding the importance of different types of information and their desire for more information.

Table 7
Importance of Information and Desire for More Information

Type of information	Importance of information	Desire for more information
learning characteristics and potential of child	4.60 *(sd 0.99)*	4.47 *(sd 0.75)*
where to receive services	4.55 *(sd 1.30)*	4.38 *(sd 1.35)*
medical conditions, physical characteristics	4.52 *(sd 1.00)*	4.39 *(sd 1.20)*
child's legal rights	4.36 *(sd 1.10)*	4.30 *(sd 1.32)*
how to teach child at home	4.32 *(sd 1.38)*	4.23 *(sd 0.98)*
typical/atypical child development	4.18 *(sd 1.05)*	4.07 *(sd 1.14)*
how to improve child's behaviour	4.14 *(sd 1.35)*	4.10 *(sd 1.64)*
how to play with child	4.09 *(sd 1.50)*	3.87 *(sd 1.04)*
parents' organisations	3.83 *(sd 1.17)*	3.63 *(sd 1.08)*
how to contact individual parents	3.38 *(sd 1.23)*	3.18 *(sd 1.20)*

importance:
5 = very important; 4 = important; 3 = somewhat important; 2 = not very important; 1 = not important
desire for more information:
5 = much more; 4 = more; 3 = some more; 2 = a little more; 1 = no more

Parents considered the majority of areas of information to be important, with the learning characteristics and potential of their child being ranked as the most important (awarded a mean rating of 'very important'/'important'). Only for those areas relating to contact with other parents did they return ratings of 'somewhat important'. In terms of their desire for more information, they indicated a general desire for more information all round, with this again being most marked for the learning characteristics and potential of their child. Table 8 indicates their preferred ways of receiving this information.

Table 8
Preferred Ways of Receiving Information

Ways of receiving	% Indicating 'yes'
receive written information	86%
attend group talks	32%
individual meetings	27%
someone come to home	46%

It can be seen from the table that by far the most preferred way of receiving information is in written form. Perhaps surprisingly, only around a quarter of the sample would like individual meetings, whilst a third would like to attend group talks and almost a half would like someone to come to their home.

What are parents' present or future concerns about their child?

Table 9 indicates the rank order of parents' present or future concerns.

Table 9
Present or Future Concerns

Area of concern	Level of concern
quality of child's education	4.56 *(sd 0.91)*
acceptance and understanding of child by others	4.43 *(sd 0.94)*
child's safety	4.42 *(sd 1.06)*
child's social development and behaviour	4.35 *(sd 1.11)*
child's progress at school	4.31 *(sd 1.03)*
receiving medical and social support services	4.27 *(sd 1.20)*
financial security of child as adult	4.18 *(sd 1.30)*
child's health	4.15 *(sd 1.20)*
development of friendships by child	4.08 *(sd 1.19)*
housing as an adult	3.53 *(sd 1.53)*
entering puberty	3.36 *(sd 1.61)*
child's sexual development	3.28 *(sd 1.55)*
child as an elderly person	3.25 *(sd 1.67)*
type of job as an adult	3.08 *(sd 1.57)*
love and marriage as an adult	3.04 *(sd 1.59)*

5 = very concerned; 4 = concerned; 3 = somewhat concerned; 2 = not very concerned; 1 = not concerned

In many respects the priority rankings returned by parents regarding their present and future concerns reflect the ages of their children (i.e. within the range 2 to 11 years) and thus the highest ranking in terms of concerns is the quality of their child's education, over which they are 'very concerned'/'concerned'. For more distant events in terms of time (e.g. those relating to adolescence and adulthood) mean rankings indicated that parents were 'somewhat concerned'. Typical comments added by parents relating to this issue of the immediacy of concerns are those given below:

> *'I try not to think about how things will be when he gets older... It's enough just worrying about how he is now.'*

> *'Puberty is the next hurdle. I haven't given much thought to concerns about him as an adult... but I will have to before too long.'*

For other parents the contemplation of their child's future was a 'luxury':

> *'Many children with the same syndrome as mine die in their teens. It would be a pleasure to worry about jobs and marriage.'*

What type of future housing would parents like for their child and how likely do they rate the different options?

Table 10 shows the preferred type of future housing which parents would like for their child and their ratings as to the probability of achieving this option.

Table 10
Type of Housing Preferred and Probability of Options

Type of housing	Level of preference	Probability
live at home with parents	3.83 *(sd 1.38)*	3.92 *(sd 1.21)*
live in a group home (10+ people) with full-time supervision	3.14 *(sd 1.60)*	2.67 *(sd 1.30)*
live independently	2.49 *(sd 1.73)*	1.77 *(sd 0.95)*
live in sheltered housing (1-2 people) with full/part-time supervision	2.09 *(sd 1.29)*	1.75 *(sd 0.86)*
live in group home (10+ people) with part-time supervision	2.06 *(sd 1.18)*	1.81 *(sd 0.93)*

preference:
5 = very preferred; 4 = preferred; 3 = somewhat preferred; 2 = not very preferred; 1 = not at all preferred
probability:
5 = very probable; 4 = probable; 3 = somewhat probable; 2 = not very probable; 1 = not at all probable

It can be seen from the table that the preferred future housing for their child is living at home with parents; this is also viewed as being the most probable option. The only other option to fall within the 'somewhat preferred' range is live in group housing with full-time supervision. However, this is seen as being only 'somewhat probable'/'not very probable' in terms of being an available option. Independent living, sheltered living or group living with part-time supervision are not very preferred and are considered to be not very probable as options.

What type of future work would parents like for their child and how likely do they rate the different options?

Table 11 shows the preferred type of future work which parents would like for their child and their ratings as to the probability of achieving this option.

Table 11
Type of Work Preferred and Probability of Options

Type of work	Level of preference	Probability
day-care	3.15 *(sd 1.61)*	3.10 *(sd 1.37)*
supported employment in an ordinary employment setting (not with other disabled adults)	2.91 *(sd 1.53)*	2.26 *(sd 1.31)*
supported employment in a work enclave (i.e. in an ordinary setting with other disabled adults)	2.89 *(sd 1.53)*	2.51 *(sd 1.31)*
sheltered workshop	2.88 *(sd 1.44)*	2.79 *(sd 1.25)*
ordinary (unsupported) employment	2.75 *(sd 1.69)*	1.85 *(sd 1.11)*

preference:
5 = very preferred; 4 = preferred; 3 = somewhat preferred; 2 = not very preferred; 1 = not at all preferred
probability:
5 = very probable; 4 = probable; 3 = somewhat probable; 2 = not very probable; 1 = not at all probable

As indicated, the preferred future employment for their child is day-care, with this also being viewed as being the most probable option. Even so, this is only rated as being 'somewhat preferred' and is considered to be 'somewhat probable'. All other options fall within the 'somewhat preferred'/'not very preferred' range and are also viewed as being 'not very probable'/not at all probable'.

Summary

A number of themes emerge from the study, with education being signalled as a major priority for parents of children with severe learning difficulties. The majority of parents in the sample are generally satisfied with their child's current special school placement and do not want a change of placement for their child. Of those parents who do indicate that they want a change of placement, the preferred option is a special class in an ordinary school. Parents want a high level of involvement in their child's education but, on the whole, do not achieve as high a level of participation as they would wish. This is particularly the case with participating in school events and activities and talking with the child's therapist. A priority for their child's learning is the acquisition of communication skills, with social, motor and leisure skills also being important. The achievement of academic skills ranks less highly with the parents in the sample and there is also less satisfaction with the teaching of academic skills than with most of the other skills referred to in the questionnaire.

In terms of other services received, parents are generally satisfied or somewhat satisfied. However, in a number of areas, around a quarter of parents express a desire for services which they currently do not receive.

Undoubtedly, the concerns of parents change as their child grows older but even for this sample of parents whose children are all under eleven years of age there are already concerns about the needs of their child as an adult. In terms of their child's future work prospects and their ability to live independently, many parents have low (or realistic?) expectations and thus the majority expect that their child will be unlikely to live or work independently or semi-independently as an adult.

Concluding comments

As far as the inclusion debate is concerned, can we conclude from these findings that parents of children with severe/profound and multiple learning difficulties prefer special schooling for their children? Given that almost three-quarters of them signalled a wish for 'no change', we probably can. As such, the indications are that special schools should remain within the spectrum of choice available to parents.

However, choice must be genuine and there was some indication in the present study of parents having to *settle* for special provision rather than actively *choosing* it - frequently as a result of perceived lack of resources or expertise in ordinary schools. Illustrative of this are the comments of one parent as cited below:

> *'I would have preferred a special class in an ordinary school but mainstream teachers are not trained to teach children with special needs and the schools are not set up to deal with the special problems of our children. I did try to push for our local school but when I saw it I realised that they just wouldn't be able to cope. There was no special equipment, not enough space and the class teacher had never taught a child like mine before... You can't just throw a child into mainstream school and hope for the best.'*

Thus, unless parents believe that their children will be safe and accepted and will receive a 'quality' education in ordinary schools, they will - like the parent quoted above - continue to support segregated provision for their child.

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